STATEMENT OF ROSCOE BUTLER
ASSOCIATE LEGISLATIVE DIRECTOR
PARALYZED VETERANS OF AMERICA
BEFORE THE
HOUSE COMMITTEE ON VETERANS' AFFAIRS
SUBCOMMITTEE ON HEALTH
ON
"AGING IN PLACE: EXAMINING VETERANS' ACCESS TO HOME AND COMMUNITY BASED SERVICES"
JULY 27, 2021

Chairwoman Brownley, Ranking Member Bergman, and members of the Subcommittee, Paralyzed Veterans of America (PVA) would like to thank you for this opportunity to provide input on the Veterans Health Administration's (VHA) Home and Community Based Services (HCBS). PVA is a congressionally chartered veterans service organization (VSO) whose members are all veterans of the armed forces who have acquired a spinal cord injury or disorder (SCI/D), such as multiple sclerosis or amyotrophic lateral sclerosis. As a result, the overwhelming majority of our members rely on the support of caregivers and home care workers to assist them in meeting their daily needs.

The demand for long-term care for veterans with an SCI/D is growing. While the life expectancy for SCI/D veterans has increased significantly over the years, so too have the secondary illnesses and complications associated with both aging and SCI/D. The number of SCI/D veterans needing long-term-care services is rising, and VA does not have sufficient resources to meet the demand.

According to the Department of Veterans Affairs' (VA) FY 2018 - 2024 Strategic Plan,[1] more than half (52 percent) of Americans over age 65 are expected to lose the ability to function independently and require long-term support services, and those with chronic conditions (diabetes, high blood pressure, etc.) or disabilities are more likely to need comprehensive health care and long-term support services to address their challenges. Also, because the number of Americans aged 65 and older is expected to increase from 46 million in 2014 to 74 million by 2030, the demand for long-term care services is expected to increase as well. If current utilization trends continue, the need for long-term care providers to care for the elderly is expected to increase as much as 79 percent by 2030.

Need for VA Long-Term Care Services

VA provides or purchases long-term care for eligible veterans through 14 long-term care programs in institutional settings like nursing homes and noninstitutional settings like veterans' homes. Long-term care includes many types of health and health-related services for individuals of all ages who have limited ability to care for themselves because of physical, cognitive, or mental conditions. They are provided in institutional settings, such as nursing homes, and home and community-based settings, such as adult foster care,

[1] Department of Veterans Affairs FY 2018 - 2024 Strategic Plan

homemaker/home health aide care, respite, skilled home care, veteran-directed home care, purchased home hospice and palliative care, and family caregiver assistance.

In February 2020, the U.S. Government Accountability Office (GAO) released a report entitled, "Veterans' Use of Long-Term Care Is Increasing, and VA Faces Challenges in Meeting the Demand."[2] The report describes the use of and spending for VA long-term care and discusses the challenges VA faces in meeting veterans' demand for long-term care and examines VA's plans to address those challenges. From FY 2014 through 2018, VA data shows that the number of veterans receiving long-term care in these programs increased 14 percent (from 464,071 to 530,327 veterans), and obligations for the programs increased 33 percent (from $6.8 to $9.1 billion). VA projects demand for long-term care will continue to increase, driven in part by growing numbers of aging veterans and veterans with service-connected disabilities. Expenditures for long-term care will increase as well and are projected to double by 2037. According to VA officials, the department plans to expand veterans' access to noninstitutional programs, when appropriate, to prevent or delay nursing home care and to reduce costs.

According to GAO, VA currently faces three key challenges meeting the growing demand for long-term care: workforce shortages, geographic alignment of care (particularly for veterans in rural areas), and difficulty meeting veterans' needs for specialty care. VA's Geriatrics and Extended Care office (GEC) recognizes these challenges and has developed some plans to address them. However, GEC has not established measurable goals for these efforts, such as specific staffing targets for programs with waitlists or specific targets for providing telehealth to veterans in rural areas. Without measurable goals, VA is limited in its ability to address the challenges it faces meeting veterans' long-term care needs.

For more than 15 years, the co-authors of The Independent Budget (IB)—PVA, DAV (Disabled American Veterans), and Veterans of Foreign Wars (VFW) have commented on VA's long-term care program, supportive services, and challenges. In its 2021 critical issues report,[3] the IBVSOs noted that there is a need for increased long-term care options to include more access to home-based services as well as additional institutional care for veterans who will need that level of care. In 2020, the IBVSOs made five recommendations:

- VA must make a multi-year commitment to the successful balancing of its long-term care services while maintaining a safe margin of community living center capacity.
- VA should publicly report VA long-term care workload and waiting times.
- Congress must address differing authorities for VA long-term care services and provide adequate funding.
- Congress should conduct oversight of VA's initiative to provide HCBS.
- Congress should request GAO conduct a follow-up report on veterans' access to, and the availability of, VA HCBS.

Long-term care services are expensive, with institutional care costs exceeding costs for HCBS. Studies have shown that expanding HCBS entails a short-term increase in spending

[2] GAO-20-284, Veterans' Use of Long-Term Care Is Increasing, and VA Faces Challenges in Meeting the Demand

[3] Congress117-IB-Critical-Issues.pdf (independentbudget.org)

followed by a slower rate of institutional spending and overall long-term care cost containment. Reductions in cost can be achieved by transitioning and diverting veterans from nursing home care to HCBS if they prefer and are able. VA spending for institutional nursing homes grew from $3.5 billion to $5.3 billion between 2007 and 2015; however, the number of veterans being cared for in this setting has remained relatively stable—partially attributed to expanding HCBS—indicating the cost of institutional care is rising. Despite doubling HCBS spending between 2007 and 2015, VA currently spends just over 30 percent of its long-term care budget on HCBS, which remains far less than Medicaid's HCBS national spending average for these services among the states. VA must continue its efforts to ensure veterans integrate into and are able to participate in their community with reasonable accommodations.

Overall, in 2020, VA's long-term care programs served 439,970 veterans. The veteran population served with these programs were of all ages, with 73 percent 65 or older and 20 percent 85 or older. Roughly one third (33.2 percent) of all veterans that used VA long-term care lived in rural areas, which is comparable to the percent of total veterans that live in rural areas and use VA. According to VA's FY 2022 budget request, VA honored veterans' preferences to receive care at home by increasing access to HCBS, serving 373,650 veterans in 2020 – a 5.2 percent increase over 2019.

Availability of VA HCBS

Veteran Directed Care Program

PVA believes that VA and Congress must make HCBS more accessible to veterans. One of the programs that should be expanded to all VA Medical Centers is the Veteran Directed Care (VDC) Program. The VDC program allows veterans to receive HCBS in a consumer-directed way and is designed for veterans who need personal care services and help with their activities of daily living. Examples of the types of assistance they can receive include help with bathing, dressing, or fixing meals. It is also for veterans who are isolated, or whose caregiver is experiencing burden. Veterans are given a budget for services that is managed by the veteran or the veteran's representative.

PVA member Steven McIntosh's current caregiver is his 86-year-old father. As you can imagine, his dad cannot do as much as he used to and his ability to care for his son will diminish as he ages further. Mr. McIntosh raised his concerns at his recent annual SCI/D exam and asked about the availability of the VDC program to provide him with additional care services, but learned the program is not currently available at his VA.

Unfortunately, the VDC program is not available at a number of VA facilities. It is currently available at only 69 of VA's 171 medical centers, with an enrolled population of about 4,900 veterans. Our members and other veterans are consistently asking for help in getting this program implemented at their VA health care facility. One PVA member has been waiting over two years for the Cleveland VA to implement the program.

VA Medical Centers must receive additional resources to help them expand programs like VDC. For example, an additional social worker who could get the program up and running at a facility could help expand the program's availability. VA must also do more to market the benefits of the VDC program to medical centers. A major benefit is that VDC is cheaper that institutional care and it also allows veterans to remain in their homes and direct their own care.

Homemaker and Home Health Care Aides

Another concern our members have voiced, is VA not authorizing adequate hours to care for their home care needs. In accordance with Title 38, 1720C subsection (d), the cost of Home Health Care Services shall not exceed 65 percent of the amount it would cost if the veteran was placed in a nearby nursing home. Even if we use costs at the higher end of the spectrum for nursing homes and home health aides, this formula should result in 50 hours or more of VA Home Care hours.

A VA physician determines and prescribes the number of home care hours a veteran needs in accordance with VHA's Handbook 1140.6 entitled, "Purchased Home Health Care Service Procedures." A physician may put in a consult for 28 hours, but the request may only be authorized for 21 hours or less. Veterans often contact PVA as the hours of care they receive are not adequate, and we must initiate an appeal to secure more hours.

In April 2018, VHA issued a Home Health Care Changes Educational Memo describing a new methodology for determining the number of home care hours veterans are to receive. The memo noted that the changes could significantly impact the amount of services available to individual veterans, "specifically [those] engaged with the Home Health Aid and Home Maker Services." While we recognize VA's challenge with limited resources and that our veterans are not the only veterans using VA long-term care, is it reasonable for doctors who know their patients the best to prescribe 28 hours, but the veteran only be authorized for 14? Is it reasonable for a veteran with a terminal disease to only receive 4 or 6 hours a week? We believe that such little home care for catastrophically disabled veterans is in fact not reasonable.

Instead, Congress must recognize that the veterans' population is aging and that veterans like PVA members are catastrophically disabled and at the same time losing regained function due to age. Veterans who must rely on caregivers, including those who have limited or no family support, have earned the right to live in their homes in a dignified and safe manner.

For veterans with SCI/D, VA provides less than 200 specialty long-term care beds. Community nursing homes are not the best option for these veterans and for those with bowel and bladder care needs and those who are on ventilators, it might even be impossible to find community nursing care. Thus, although PVA supports providing additional specialty care long-term care beds within VA, robust HCBS benefits would help many PVA members delay or avoid institutional care.

Workforce Shortages

Even when veterans have access to HCBS, it can be challenging to find home care workers. PVA member Stanley Brown, who became a quadriplegic following a service-connected injury in 1996 is completely dependent on caregivers to get him in and out of bed, dress him, feed him, provide his daily bowel and bladder care, and give him his medications. He is enrolled in the VDC program but finds securing and managing caregivers is almost a full-time job.

In Mr. Brown's 20 plus years of using caregivers, he has hired and managed caregivers on his own. Like many veterans in his position, caregivers come and go regularly because the amount he can pay is so low and numerous agencies or people are looking for the same workers for hospitals, nursing homes, and private homes. Over the past 10 years, he has had to screen nearly 450 potential caregivers.

Veterans have the option of using an agency to help them find a caregiver, but that greatly reduces the funds the veteran has available for the hours of service they need. Agencies typically will charge 20 to 25 percent above what they pay their worker. So, while the veteran may be paying out the VA authorized limit of $20 per hour, the actual worker will be making $12 or $13 per hour.

The shortage of caregivers or home care workers is not unique to VA. Acute shortages of home health aides and nursing assistants are cropping up across the country, threatening care for older Americans and those with serious disabilities. A vigorous national effort is needed now to help curb the effects of these shortages and bolster the direct care workforce. The President's American Jobs Plan calls for robust investments to expand access to Medicaid HCBS and strengthen the workforce through higher wages, better benefits, and sector-based job training and supports.

Legislation like H.R. 2999, the Direct CARE Opportunity Act, and S. 2344, the Supporting Our Direct Care Workforce and Family Caregivers Act, would also expand workers' earning potential and provide the financial assistance for transportation, childcare, and housing that direct care workers need to stay in their jobs.

Increasing the pay for essential caregivers is a necessary component of attracting and retaining a diverse set of people to provide HCBS but raising pay alone is not sufficient to solve the crisis we face. Utilizing multiple strategies such as raising public awareness about the need and value of caregiving jobs, providing prospective workers quality training, and developing caregiving as a sound career choice are a few of the other changes that could help turn this problem around.

As Congress and the Administration work to expand access to home-based services and stimulate greater participation in direct care roles, VA should act similarly to ensure that veterans have uniform access to noninstitutional long-term care services across all medical centers.

Caregiver Assistance While Hospitalized

For veterans with catastrophic disabilities, the need for a caregiver does not go away when a veteran is hospitalized. Neither community hospitals nor VA Medical Centers are adequately staffed or trained to perform the tasks an SCI/D veteran needs. Oftentimes, the staff are not adequately trained in bowel and bladder care, proper transfer techniques, skin assessment, or other critical care needs. In some cases, its simply the lack of available time to properly treat the patient.

Anne Robinson, a PVA member living with quadriplegia, says the most challenging time for her husband and her caregiver is when she is hospitalized. Because of the extent of her needs, one of them must always accompany her because the nursing staff, no matter how competent they are, cannot meet the demands that her body requires. In order to cough, she has to have someone physically manipulate her chest repeatedly. To go to the bathroom or take a shower, it takes somebody being physically present for 3-4 hours, both things that nursing staff are not physically able to do or cannot do because of the extent of time it takes to do them properly. The last time she was hospitalized, she had an anaphylactic reaction to an antibiotic, which resulted in a code. If her husband had not been with her, she might not be with us today.

Factors like this cause Mrs. Robinson, Mr. Brown, and another PVA member, Steven Kirk, to require access to their personal caregivers whenever they are hospitalized. However, VA will not authorize payment for caregivers when a veteran is hospitalized. For Mr. Kirk, who is a quadriplegic, the effect of going into a hospital and losing his caregiver would be catastrophic. Mr. Kirk was recently taken to a community hospital and separated from his caregiver. He was alone and unable to call for help. He has been paralyzed for nearly 42 years and during that time he has gone through 50 or more caregivers.

The caregivers for veterans like Anne, Stan, and Steve must be paid so they, and other veterans like them, will have access to their caregivers while they are hospitalized and so that they will be able to swiftly return to their homes once released. VA programs should recognize that hospital care does not contemplate the levels and type of care that veterans with catastrophic disabilities must receive. As it stands, veterans may pay out of their own pocket for the caregiver's time, or the caregiver may simply come even though he or she is not being paid because they know the importance of the care they provide to the veteran's health. VA must also recognize the importance of this care and not shift the burden to the veteran or their caregivers.

Other VA Long-Term Care Programs

Family Caregiver Program

The VA MISSION Act outlined a two-phase approach for implementing the expansion of VA's Program of Comprehensive Assistance for Family Caregivers (PCAFC). The law required the first phase to begin on October 1, 2019, approximately 16 months after the law was enacted. However, due to Information Technology delays and failures, VA did not begin

the first phase – which includes eligible veterans who became severely injured or ill on or before May 7, 1975 – until October 1, 2020, a full year later than the law required. As a result, the second phase – which will include veterans who became severely injured or ill between May 8, 1975, and September 10, 2001, will not begin until October 1, 2022, two years later as required by the law. We understand the phased approach is specified by statute, but these prolonged delays are further straining caregivers. PVA supports expediting the expansion of VA's PCAFC because these veterans and their caregivers should not have to continue waiting for this critical support.

Medical Foster Home Program

PVA also supports funding the Medical Foster Home program. Under the program's current structure, VHA does not have the authority to pay for these services; therefore, the care provided through the program is at the expense of the veteran, their family, or legal representative. We call on the Committee to approve legislation like the Long-Term Care Veterans Choice Act introduced last Congress authorizing VA to cover the cost of Medical Foster Home care, which is less costly than nursing home care.

In closing, VA needs to rebalance its existing programs to ensure greater numbers of veterans can receive long-term care services in their homes. In doing so, VA can prevent or delay placement of veterans in nursing homes and reduce costs. More importantly, it will help keep veterans in the familiar setting of their homes, surrounded by their loved ones. PVA appreciates this opportunity to comment on some of the HCBS programs VA provides. I would be happy to answer any questions you may have.

Information Required by Rule XI 2(g) of the House of Representatives

Pursuant to Rule XI 2(g) of the House of Representatives, the following information is provided regarding federal grants and contracts.

Fiscal Year 2021

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $455,700.

Fiscal Year 2020

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $253,337.

Fiscal Year 2019

Department of Veterans Affairs, Office of National Veterans Sports Programs & Special Events — Grant to support rehabilitation sports activities — $193,247.

Disclosure of Foreign Payments

Paralyzed Veterans of America is largely supported by donations from the general public. However, in some very rare cases we receive direct donations from foreign nationals. In addition, we receive funding from corporations and foundations which in some cases are U.S. subsidiaries of non-U.S. companies.